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ABSTRACT

Addressing the lack of cooperation between early intervention programs and the rural health community, this monograph presents eight papers by educators and health professionals who identify specific problems and offer solutions in the form of effective collaboration techniques and model programs. Papers by Susan Hastings and Stewart Gabel summarize physician attitudes toward early intervention and suggest ways to obtain physician involvement. Suggestions for improving physicians' cooperation include informing them of intervention program services and convincing them of program validity. Papers by Charlene Rydell and Ruth Jones, Stephanie Parks, Sharon Kiefer, and Mary Morse and Barbara Kruger describe four model early intervention programs which successfully collaborate with local medical professionals and/or community hospitals. Topics include initial planning, program design, coordination with existing services, linkage with hospitals, staff recruitment, funding sources and program effectiveness (increased physician referrals, lower age of new referrals). Papers by Esther Tesh and Sarah Strauss and Kenneth Axtell provide an overview of the administration, organization, and priorities of community hospitals and are intended to help non-medical professionals work within that structure. Information includes functions of 19 hospital staff positions and basic steps to follow when communicating with medical staff concerning a particular child admitted to the hospital. (JHZ)

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MAKING IT WORK IN RURAL COMMUNITIES

Effective Collaboration Among Health Care and Education Professionals: A Necessary Condition for Successful Early Intervention in Rural Areas

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A Rural Network Monograph
Coordinator: Sharon Kiefer
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About the Rural Network Monographs

The State of the Art Task Force has as its responsibility the collection and distribution of information related to effective strategies for delivering services to rural young handicapped children and their families. During 1980-81, a series of monographs was undertaken by contributors across the country under the editorial direction of Patricia Hutinger. A second series was began in 1981, again under the editorial direction of Hutinger. Contents of the two series of monographs (see back cover) reflect the most pressing needs of rural handicapped children's early education programs. Other topics are under consideration by members of the Rural Network and will be forthcoming.

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OSE Project Office, Sandra Hazen

November 1982
The Rural Network
Western Illinois University

A RURAL NETWORK MONOGRAPH

EFFECTIVE COLLABORATION AMONG HEALTH CARE AND EDUCATION PROFESSIONALS: A NECESSARY CONDITION FOR SUCCESSFUL EARLY INTERVENTION IN RURAL AREAS

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November, 1982

"I have talked to the doctors in our community about referring the families they serve to our infant intervention program after discovering a baby has a handicapping condition, but they just seem to ignore my request." "The doctors in our town don't give our program any credit at all." "I have so many questions; it would be great to know a physician or a nurse from whom I could get some answers. If only I felt able to give someone in the medical community a call . . ."

These are but a few of the commonly heard laments that are expressed by education professionals in rural areas across the country who staff or direct intervention programs for children with handicaps or developmental delays. Isolated from other intervention programs because of their geographic location, these professionals do not have easy access to large resource centers or universities for the most part, yet they are intimidated by one of the best resources available for finding and helping children with handicapping conditions and their families: the physicians in their area. Educational personnel tend to feel that the medical community is uncooperative, very difficult to communicate with, and extremely busy -- too busy to give of their time, energy and expertise to educational professionals who are serving the same infants and families as the medical personnel.

Is this a fair assessment of the situation? Are physicians and other medical personnel antagonistic and/or unresponsive toward nonmedical professionals? Sometimes they are! But is this, in part, a stereotyped attitude that has developed toward physicians? Perhaps if more positive approaches were to be employed, medical professionals, who have similar concerns as educational service providers -- the health, well-being, and best possible chance at life for the children to whom care is provided -- would cooperatively work with intervention programs in achieving these goals.

These questions and often seemingly frustrating situations are what have been examined in the compilation of the monograph. Interestingly enough, optimistic and helpful results emerged from the analysis. After the review of papers submitted by various medical professionals, including physicians, nurses, and hospital administrators, and from education professionals who direct or are on the staff of intervention programs, the conclusion was reached that there are communities where the medical personnel work hand-in-hand with intervention programs. There are limitations, yes, to what can be expected, but once some of the barriers between the two disciplines can be removed, the needs of each understood and a coopeative partnership achieved, then benefits can be realized.

November, 1982 Bonnie Smith-Dickson

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CRITICAL CONSIDERATIONS: AN OVERVIEW OF COLLABORATION

Introduction

The two papers in the following section examine the problems which contribute to the lack of cooperation between education programs and the medical community. Hastings, the director of a Pediatric Resource Project, after emphasizing the necessity for early intervention and explaining why medical centers are the best source for referrals, examines the reasons for the lack of cooperation from medical personnel. An understanding of the basis for physicians' reluctance is essential, believes Hastings, before strategies can be utilized to overcome the lack of communication and cooperation.

In the second paper, Gabel, a pediatrician, presents his personal view concerning the lack of communication and coordination that exists between medical and educational professionals, agreeing that often times the complaints of non-medical service providers are warranted. However, he believes, that today, more than ever, physicians are aware of the importance of early intervention. Gabel, while underlining the necessity of non-medical professionals to assume more than an equal share of the responsibility for disintegrating communication barriers, provides suggestions to facilitate physician involvement in early intervention programs.

ACHIEVING A WORKING RELATIONSHIP WITH A MEDICAL CENTER

Susan N. Hastings

Necessity of Early Intervention

In order for professionals to provide the highest quality of services to handicapped children and their families, it is essential that identification and treatment begin as early as possible. Those involved in early intervention believe that early identification and treatment are essential for several reasons. First, infancy is clearly the time of life in which the greatest knowledge is gained in the shortest amount of time; consequently, the learning done in infancy is necessary to the optimal development of any individual. This learning is, of course, dependent on the environment created by the handicapping condition and by the handicap itself. Therefore, a child with a mental, motor, or sensory handicap will in all probability be deprived of many fundamental learning experiences in the first years of his life because first, his environment is affected by others' response to his handicap and second, his ability to respond to that environment is diminished because of the handicapping condition.

Educational research has indicated that the rate at which children acquire knowledge and skill is greatly accelerated during the first two years of life, that this acceleration begins to diminish at about two or three years of age, and that maximum use of the first years of life is essential in a child's optimal development. This makes early education very important for individuals who are either mentally or physically handicapped, since in order to reach their fullest potential, the natural time of accelerated learning must be used. A delay in learning during the infancy period resulting from the handicapping condition can hinder future successes and limit the potential of the handicapped individual. Those who are involved in the education of the handicapped or at-risk infant strongly believe that taking advantage of these early years must be a central concern as evidence of the importance of the infancy period is accumulated.

Furthermore, early intervention and education can be viewed as an important preventative measure. If parents and educators can identify potential problems early enough, and if all at-risk infants can become involved in proper developmental programs, through proper physical therapy, education, and counseling, these problems can be diminished or at least minimized. For educators, then, the earliest possible start in the intervention of handicapped infants has become an important objective in the treatment of the handicapped individual.

Unfortunately, all too often, the at-risk child does not come to the attention of community educational projects until months or even years after intervention could have begun. What must be considered however is that locating and recruiting the child and family who may benefit from

their services is a problem that faces many community-based programs. Unfortunately, many times the educator attempting to locate and assist the high-risk or handicapped infant, and thus begin intervention at the earliest possible moment, encounters resistance or lack of consideration from the sources that could and should prove most useful in the search.

Lack of Cooperation From Medical Centers

Perhaps the organization that most frequently has contact with high risk infants and provides the essential and immediate medical care is the university or regional medical center. A typical medical center comes in contact with these infants and their families in a variety of ways. Most medical centers have a neonatal intensive care unit in which newborns with life-threatening problems at birth are treated and from which they are eventually discharged to their home communities. In addition, most medical centers have some type of follow-up clinic (often called a premie clinic) that continues to monitor the progress of those infants who were born prematurely or in an at-risk situation. A pediatric outpatient clinic at a medical center also sees some families with infants that would benefit from early developmental intervention. Pediatric departments in medical centers typically have a variety of other services such as perinatal projects, developmental clinics, or other follow-up services, all of which are dedicated to providing quality medical treatment to children, and all of which have access to information concerning those children who would benefit from early intervention.

Unfortunately, these resources and facilities have not cooperated as fully as they might have with the educator in identifying and locating the high-risk infant in rural communities. All too often, the medical center and the community-based programs have not worked together at all and, in fact, the educator who approaches the medical center has often encountered much resistance.

Examining the nature of a medical center and some of the reasons for this resistance may be helpful to the educator who wishes to establish a mutually helpful relationship with the medical center in his region. By understanding why medical centers in the past have not enthusiastically embraced community programs, the educator will be able to develop an effective strategy to overcome some of the resistance, thereby making inroads for the referral of the high-risk or handicapped infant to his program and establishing a mutually beneficial dialogue between the medical center and the intervention program. A close and supportive working relationship between medical centers and community programs is essential in order for the families and children to receive the comprehensive treatment needed for optimal prognosis of the handicapped infant. By understanding some of the barriers that have prevented this close relationship, the medical and educational communities can perhaps begin to work more closely with each other.

Physicians' Unwillingness to Label

The reason often given by physicians for not immediately referring at-risk infants to developmental programs is that they do not want to label prematurely children with problems. Since most handicapping condi-

tions are not immediately identifiable at birth, physicians often feel that any early labeling or identification may result in the self-fulfilling prophecy. The very young child who is started in an intervention program may have to live with the stigma that is often attached to those who participate in special services. More importantly, the tendency of parents to treat a handicapped child differently may, many physicians feel, lead to atypical parenting which might unnecessarily result in developmental problems which could have been avoided.

Certainly, the physicians' concern about needless labeling of an infant is legitimate and the benefits that result from early and immediate intervention must be weighed against the possible negative results of the stigma attached to the inevitable "special" nature of children in developmental programs. Certainly, the kind of developmental services that are provided by most community-based programs could be beneficial to any family, but since those services must necessarily be limited, only those infants with the most pressing needs are selected, and some labeling does result. The fear that early labeling will result in atypical parenting is less legitimate, however. Developmental programs are usually as concerned with teaching proper parenting as they are in the development of the infant, and parents would likely benefit from their child's participation in a developmental program. Spoiling and over-protection would be much more common in a parent whose child is not participating in a program where proper parenting is a concern. Certainly, any dangers in early labeling are outweighed by the obvious benefits, and to deprive an infant of the educational opportunities of services during the important learning years in order to avoid labeling is a trade-off that should not be made.

Physicians' Lack of Trust in Other Programs

Although the reluctance to label children before a definitive diagnosis is possible is the reason often given by medical professionals, several other reasons are equally important in understanding why developmental programs and medical centers have not worked as closely together as they might have. Medical centers have a tendency not to trust programs and services other than their own to provide adequate care. They are traditionally the centers for research, and they are, therefore, very up-to-date on what is being done in the medical disciplines. Because most of the physicians are also professors, they are continually researching and teaching the latest medical information, and they are on the cutting edge of what is going on in the field. It is because of this ongoing knowledge and expertise that the medical center is such an important part of the treatment of the handicapped or high-risk infant.

Unfortunately, the very qualities that are its strengths are also responsible for the fact that many of the medical center's professionals are skeptical about community developmental programs which they perceive to be less sophisticated than their own. The medical professionals who choose to work in the medical center environment do so because of the opportunities to do research and teach as well as to treat the complex problems which are referred to them. Because they are sincere, highly motivated scientists, their approach to any problem is based on the scientific method: their decisions are based on effectiveness data. Too

often, community or social services do not present their programs scientifically or professionally, and many medical professionals have justifiably skeptical attitudes about the value of these services.

Physicians' Lack of Knowledge About Early Intervention Programs

This skepticism is closely related to the third and, probably, most important reason that medical centers have not worked as closely with community services as educators might have wished. All too often medical professionals are not familiar with educational and developmental literature or with the services and benefits that are offered through early intervention programs. Many medical professionals lack information about community programs, or about the community's educational professionals. Often convincing physicians of the value of early intervention services is all that must be done to insure their cooperation and referrals.

Strategies for Overcoming Resistance from a Medical Center

With a proper understanding of the resistance that a medical center's personnel might feel towards a community service, an educator can be better prepared to approach a medical center in his region about infant referrals and intervention. Several techniques for a successful approach become apparent when the reasons for the resistance are understood. First, if the medical professionals are concerned about the dangers of early labeling and self-fulfilling prophecy, an educator must be prepared with data that proves that the benefits that will be derived from the program outweigh those possible problems. The educator must be prepared to sell the program that he is representing with clear evidence of what it has accomplished with other infants and families. Printed information about the program itself, and the services will help to establish program credibility.

While the educator is trying to convince the doctor or medical person of the usefulness of the community service, he must do so in a manner that will speak to the trained, medical professional. A sentimental approach concerning the emotional needs of the child and the family will not reach a physician with the impact an educator might wish. Medical professionals are well aware of the potential tragedies involved in the lives of the handicapped infant and his family. However, they will be more impressed by and will act on a concise and rational presentation which assures them that the early intervention program is being conducted on a sound theoretical basis.

Provide Evidence of Program's Success

An educator who wishes to establish close working ties with a medical center must convince that center's physicians that the field of education itself is a professional and valid field. A brief, well-prepared presentation that is filled with evidence of the success of the program or statements from parents concerning the program's success can be used effectively as evidence of a program's worth, especially when the physician has worked with the family. Parents can even be asked to write directly to physicians, so that their letters will serve as additional proof of the program's impact. A parent's account will often prove effective when an educator's might not.

Once the educator has compiled the evidence of the program's effectiveness in a convincing presentation, it can be taken to the medical center in a variety of ways. The social service division of a medical center is often the best place to begin attempting to get referrals to a community-based developmental program. Almost any university or regional medical center will have a social service department that is responsible for discharge planning and follow-up support services. Social workers will, in many cases, be assigned to work with families on an individual basis to provide the necessary support after the birth of an at-risk child; letting them know of community-based programs is an effective way of obtaining referrals. Once again, it is important that the educator provide concrete evidence as to his/her program's effectiveness.

Impact the Nurses

If getting referrals from the medical center is the sole objective, the social service contact may be sufficient, but if the educator wishes to enlighten the medical community about the developmental needs of infants and families, other strategies must be employed. One technique that can prove useful is working directly with nurses. Often nurses will establish close enough ties with families so that they will be able to refer individual families to programs with which they are familiar. Simply disseminating the information about a community program among nurses in newborn intensive care units or in follow-up clinic can result in infants and families being referred to the program. Most nursing departments also have ongoing inservice training, and establishing ties with the training coordinator and convincing her of the importance of early intervention could lead to an opportunity to train an entire nursing staff.

Provide Workshops

A possible technique for approaching the physicians in a medical center about the importance of early intervention and referral for at-risk and handicapped infants is to provide continuing education workshops through the university. This will probably prove most successful if the workshop is conducted by a member of the medical faculty, such as a behavioral pediatrician, who is sympathetic toward early intervention goals. Educators should become familiar with those medical professionals in the community who support educational programs for handicapped and at-risk infants. These physicians provide the necessary link between the medical and educational communities and can do much to bring the two into a closer working relationship.

Conclusion

Above all, the educator should never forget how useful the medical center can be in obtaining the necessary referrals that will enable his service to reach the greatest number of handicapped children. It is the medical center that has the best information about children who need early intervention. Only when the medical center, the community, and educational service organizations work closely together can those children who will benefit from early intervention be referred to the necessary agencies. If establishing this working relationship requires that the

education professionals convince the medical center of the validity and worth of its program, and if the educator must do a little "wooing" in the process, certainly the benefits that will result to the child are worth the time and effort that are required.

FACILITATING THE INVOLVEMENT OF PRIMARY CARE PHYSICIANS IN THE CARE OF DEVELOPMENTALLY DISABLED CHILDREN BEING TREATED IN COMMUNITY-BASED PROGRAMS

Stewart Gabel, M.D.

Professionals outside the medical field who provide care to developmentally disabled and multi-handicapped children frequently complain about the lack of communication and coordination between themselves and the physicians. Physicians, whether community or academically based, are often described as being unresponsive to the psychosocial and family needs of their patients. They are said to be too busy to spend time talking with both the parents and the non-medical service providers. Often they do not return telephone calls from personnel outside the medical field or they return them late. They are usually not trained in developmental or behavioral problems of children and do not seem to care or concern themselves with these issues. When many physicians speak with parents, they are either too blunt and tactless, thereby causing the parents to become angry and dissatisfied; or they refuse to speak to the actual issues (such as mental retardation) in layman's terms, thus leaving the parents confused and uninformed; or they use jargon in speaking with both non-medical service providers and the parents, thus hindering communication rather than enhancing it.

Personal View of Physicians' Lack of Involvement

As a pediatrician who previously worked as the director of a multidisciplinary child development clinic, I came to feel that the statements made above, while obviously generalizations and obviously not representative of all physicians, are unfortunately true in many cases. The clinic in which I worked provided, among other services, multidisciplinary evaluations for children suspected of having a variety of development disorders. When compared to educators, social service workers, and public health department personnel, private physicians were the worst sources of referral. They often delayed referring for comprehensive evaluation or did not detect developmental or behavioral problems until they were advanced.

Physicians, unless they have a particular interest in or training in developmental and behavioral problems of children, are often uninvolved and uninterested in these prevalent disorders. Parents often leave discussions with both academic and primary care community physicians with little understanding of their child's problem, with little confidence in the physician's interest in their child, and with feelings of anger or inadequacy in their inability to effectively communicate with the physician. Non-psychiatric physicians, despite claims of interest in the family and the social aspects of medicine, tend to focus on physical problems. They do return calls of other physicians promptly, but when professionals outside the medical field leave messages with office personnel or answering services, they go unanswered too often.

These characteristics of many physicians who do not work directly with programs that are concerned with the medical, developmental, and educational therapies of children with handicaps and developmental disabilities are disturbing. On the brighter side, however, there seem to be some signs of change. In the last several years, pediatrics has become very much involved in what are called "developmental" and "behavioral" aspects of pediatric care. Pediatrics departments at medical schools have added faculty who have been trained in or who have interest in these areas. Particular professional sub-speciality designations within pediatrics are becoming more and more recognized in these fields. Recent educational programs sponsored by the American Academy of Pediatrics (A.A.P.) have emphasized bio-social, developmental and behavioral problems. Numerous books and journal articles reflect this new interest among pediatricians.

Non-medical service providers have indicated that they feel physicians entering the field today have a greater interest in and awareness of problems in developmental and behavioral areas than has been found among physicians who have been practicing a number of years. There also seems to be a growing consensus that several medical disciplines, including pediatrics, have been training more physicians than the population as a whole needs. This anticipated "doctor glut" has perhaps caused physicians currently in practice and those who are being trained to develop interest and expertise in areas such as developmental and behavioral problems that went relatively unnoticed in the past. Another determing factor in this movement is that parent groups, interested public and civic organizations, and society at large have been showing evidence of increasing awareness of developmental problems and behavioral disorders in American children and this interest naturally influences large governmental organizations and medical programs.

Therefore, while physician involvement in the care of children with multiple handicaps and with non-medical service providers has been rather mediocre, there are hopeful trends for the future. The non-medical service provider to children with handicaps may view the coming years with optimism in regard to working cooperatively with physicians who are involved in the care of children with handicaps.

The remainder of this paper will offer suggestions for non-medical service providers in their attempts to further facilitate the involvement of primary care physicians practicing in local and rural communities in programs for children with handicaps or developmental disabilities.

Suggestions to Facilitate Physician Involvement

Physician as a Member of the Intervention Program's Staff

If at all possible a physician should be an integral part of the actual staff serving the handicapped child in the community-based facility. This may be via a full or part time funded position, on a consultant basis, or on volunteer status. Such a person (who often does not need to be full time), is invaluable in helping to coordinate and communicate information to other physicians and in explaining the program and its efforts at medical

conferences, formal or informal meetings with other physicians (e.g., within the local hospital), and to other professional contacts. Such a person, even if only on the premises of the treatment program for a short time, can provide informal advice/information to the non-medical personnel on the program's staff and be available to answer questions as well as serve in the above noted liaison capacity to other community physicians. Questions about whether particular movements are "seizures" or whether additional sub-specialist medical referrals are necessary can all be answered when a physician is regularly present at staff meetings or patient conferences.

Medical Professional in a Medical Coordinating Role

If it is impossible to have a physician directly affiliated with the staff, however, it is important to have a medically oriented person such as a nurse or nurse practitioner serving in a medical coordinating role. This person should try and set up meetings or talks at the local medical society, on hospital grand rounds, or at the local health department. The physician, if available, or the nurse or nurse practitioner should contact the heads of various medical organizations and ask for time to explain the function of the program and discuss the need for local physician involvement in the program. The chief medical provider at the community-based program, whether a physician, nurse, nurse practitioner, or other medical person, should contact the pediatrics or family practice departments of the nearest medical school. Initially, through the chairperson of the department, the particular physician or physicians on the staff who are interested in or who have been trained in developmental problems of children can be located. This person, to whom the particular needs, strengths and weaknesses of the community-based program should be explained, can offer advice and possible help in facilitating the identification, awareness and cooperation of physicians working in the area. The developmental pediatrician on the medical school staff, for example, may thereby be a valuable resource even if the medical school is at a considerable distance from the rural community-based program. At times it may also be possible for pediatrics residents to serve in a rural and/or community-based program on a "community rotation," thus providing a link to the medical center and additional medical input.

Sources of Information About Physicians With Child Development Interests

Other sources of information about physicians who have particular interests in developmental and behavioral problems can be obtained by contacting local medical organizations to inquire about pediatricians or family physicians with interests in these areas. The American Academy of Pediatrics, located in Evanston, Illinois, may also be contacted. The Academy has a listing of those physicians who are interested in child development, and it may be that some physicians on this list (which is growing rapidly) are located in the vicinity of the community-based program. The American Academy of Pediatrics also has state affiliates. The addresses and telephone numbers of these state organizations can be found by contacting local hospitals, health departments, medical schools or the

national organization. These state organizations can be helpful in identifying pediatricians at the local level who have the interest and expertise in developmental and behavioral problems.

Awareness Strategies to Use With Physicians

These efforts can be thought of as community organization work. In locating physicians who would be effective and willing to work with the community-based program, one is also generating information and knowledge about the program to other doctors who may not wish to be greatly involved, but whose input through their involvement with individual patients will nevertheless be essential at some point. The more physicians who know about the program through various sources (personal phone calls, visits, informal discussions with other physicians, or publicity through local newspapers) the better off the program is.

As a part of these efforts to have physicians involved with the program, it should be routine practice to invite physicians in the community to attend staffing on problem cases with which they are involved. Even though often times they will not be able to attend the staffing, the knowledge of the program's involvement with the child, and the staff's desire to work cooperatively often have beneficial effects. It is also not surprising that when parents of the child with a handicap discuss the child's participation in the community-based program in positive terms with their physician, the physician becomes much more enthusiastic.

It is also advisable to send periodic letters, reports or progress assessments to the children's doctors, even if the program staff feel that the physicians are involved only in the very technical, physical aspects of the care and that their involvement does not overlap the habilitative, educational or psychosocial involvement of the community-based program. Physicians are often slow to warm up to the efforts of non-medical personnel who provide additional care to their patients. Nevertheless, efforts at communication and coordination ultimately will produce good results.

Communication Barriers: A Two-Sided Problem

Finally, it may be helpful to examine the reluctance and inhibitions that non-medical service providers feel in initiating or expanding conversations with doctors. It is surprising how many professionals of considerable expertise, who have very pertinent concerns about a child, who after all is the mutual patient/client of the physician in the community and the community-based program, are reluctant to ask the physician questions, or are shy about encounters with the doctor. They often feel their questions are unintelligent or awkward, or that they have no business taking up the physician's time. Many of these attitudes are related to the common negative qualities ascribed to physicians that are listed earlier in this paper. But the problem is two-sided and non-physician service providers must bear their responsibility for lack of appropriate assertiveness and self-esteem in their acceptance of the "God-like" image which they have so readily granted the physician, who, in most cases, does not want or like this image at all. The non-physician service provider must realize that what he/she has to say or question, or what he/she wishes to inform

the physician of is important. Otherwise the phone call, letter or personal contact would not or should not have been made. The non-physician provider is requesting or providing input which is necessary in order to serve the mutual patient most beneficially.

Physicians, like non-physician providers, may be limited in time, patience or involvement at any hour. This only means that the conversation needs to be deferred to a more convenient time, but should be pursued until both the physician and the service provider are satisfied that they have been helpful to one another and their communication will result in improved care for the child. When the service provider's or the physician's conversation and manner are tactful, concise and direct, satisfactory results are in all likelihood possible. Appropriately persistent and assertive queries on both sides may be necessary at times. In any event, what is not understood must be clarified in terms that are clear to all involved. If communication does falter, the cause may be due either to the physician or the service provider. It is the responsibility of both to attempt to remedy the situation. Some physicians may not have the interest, sensitivity, ability or time to take on these tasks of involvement and communication that serve the best interests of their patients and facilitate the smooth workings of the community program for children with handicaps. This should not, however, deter other physicians and the service providers from making appropriate efforts on behalf of the children and families who so need their coordinated/cooperative services.

EXAMPLES OF EDUCATION AND HEALTH CARE COLLABORATION

Introduction

Four model early childhood handicapped intervention programs are described in the following section. The first model program is a hospital-based development/therapy program for one to four year olds, co-directed by the authors of the paper, Rydell and Jones. The authors describe ways the community mobilized its local resources to implement a plan for a centrally located facility and, in doing so, established linkages among the serving agencies in the area. The operation of the program is summarized and the advantages of the hospital setting are detailed.

The other three intervention programs illustrate the means by which necessary services may be provided to young children with handicaps and their families by combining efforts of the education and health care agencies. Parks examines an infant intervention program in Virginia which was initiated by a pediatrician, the director of a child development clinic, who recognized the need for such a program since no comprehensive intervention existed in the community. The Clinic had nowhere to refer a child after diagnostic work-ups. Kiefer describes a small community-based program, also in rural Virginia, which accomplished three major objectives after gaining the confidence of the medical community. After an active awareness campaign, with medical professionals as the primary targets, the Child Development Resources Center increased physician referrals 100%, reduced the average age of referral from 18 months to less than six months of age, and became a training site for primary care pediatric medical residents.

Morse and Kruger present the historical background of the MICE Project in New Hampshire which is a model of service agencies compiling resources and energy to meet the health, medical, therapeutic, education and social needs of young handicapped children. Through an explanation of the MICE Project staff's work as an advisory team, which facilitates cooperation between health care personnel and educators, Morse and Kruger illustrate the benefits to the educational system that collaboration can bring.

COMMUNITY ORGANIZATION TECHNIQUES IN PROGRAM DEVELOPMENT: ESTABLISHING A CHILD DEVELOPMENT PROGRAM IN A SMALL COMMUNITY HOSPITAL

Charlene Rydell
Ruth Jones

"Hospital Turns Fun for Handicapped Preschoolers" ran the headline in a recent issue of a local Maine newspaper. The article described a unique Child Development-Therapy Program for handicapped infants and preschoolers which had just opened at a small community hospital in Bath, Maine. A drab hospital ward had been transformed into a vibrant, challenging learning center where each morning developmentally delayed children ranging in age from one to four years were engaged in carefully planned group activities and individual therapy. A year before, parents and professionals were feeling frustrated and discouraged at the lack of an appropriate comprehensive service for the area's young children with developmental disabilities. Now they were full of excitement and enthusiasm for this innovative education and treatment program designed specifically to meet the local need.

The sequence of events in this interim period is the organizational case history of a successful attempt to mobilize local resources by drawing upon many segments of the community, including those not previously involved with handicapped children. The ultimate goal was a service which not only would be accessible to families in a rural area, but also which would be built through local participation in the planning and implementation process. The proposed plan needed to be relevant in the context of current Maine laws, to take advantage of all possible funding sources, and to fit into the local life pattern.

Maine's Plan for Services to Young Handicapped Children

Special education laws in Maine do not require local education agencies to serve children under age five, and only a handful have chosen to do so. Instead, there are a number of public and private, state and local agencies as well as individual practitioners, each with separate eligibility criteria, methods of delivery, and referral systems. Each region of the state presents a different picture. In some areas, the service pattern may resemble a puzzle with many pieces missing. In others, there is a fairly complete mosaic of programs which coexist, but have few interconnections and no specific responsibilities for coordinating their efforts. Since at any one point in time, handicapped children and their families may require several modes of intervention, a major problem has been the integration of multidimensional educational, medical, therapeutic, and support services.

To alleviate this situation, three state departments (Mental Health and Retardation, Education and Cultural Services, and Human Services) have collaborated to establish several projects whose specific goals are to

coordinate existing services for preschool handicapped children, to assess unmet needs in their respective geographical regions, and to spearhead initiatives aimed at closing those gaps. At the present time, seven projects are funded on an ongoing basis by the Department of Education and Cultural Services and administered through an inter-departmental coordinating committee. Legislation was passed in 1980 stating the intention of gradually increasing the number of projects to cover the entire state, with expansion beginning in the 1982-83 fiscal year.

Overview and Objectives of the Region

Although bordering two projects and sharing some services with one, the catchment area for the new hospital program does not receive any state funds for coordination of services to preschool handicapped children. This area, generally referred to as the Bath-Brunswick Region, includes 12 towns and a population of approximately 50,000, with two main commercial-service centers, outlying small villages and farming districts, and several long coastal peninsulas. Realizing the advantages which surrounding communities enjoyed through their coordination projects, the Brunswick School Department took the initiative in early 1980 to bring together parents, representatives of surrounding school districts, preschool teachers, and agency personnel to explore alternative funding sources. An Ad Hoc committee was formed, and six months later the school department launched Project SEARCH (Seeking Early Assessment and Resources for Children with Handicaps) with a small grant from the Maine State Planning Council on Developmental Disabilities. The new project sought to locate families with handicapped children under school age, to encourage early referrals by physicians, and to begin the process of improving the coordination and contact between existing agencies serving young children with special needs.

The Service Structure in the Bath-Brunswick Region: Autumn 1980

One of the first tasks of Project SEARCH was to contact all individuals and organizations potentially reaching developmentally disabled young children to inform them about the new project and to collect data on their particular service. In this way, an overall picture of resources in the region was developed. It soon became apparent that the range of programs and number of professionals was quite impressive by comparison to many parts of the state. However, there was little logic to the referral mechanism, a good deal of rivalry, and no system for regular ongoing contact, even among those involved with the same family. The sum of the parts did not necessarily make a whole. Some families were receiving service from several sources, while others fell partially or totally through the cracks. Certain physicians habitually made referrals to the same therapist or to only one agency; others delayed referrals either for lack of knowledge about appropriate resources or for philosophical reasons. Agency names and program labels could be misleading and result in the unintentional exclusion of some potential clients. For example, the Bureau of Mental Retardation Home-Based Child Development Program, available without cost to all developmentally delayed children from birth to age five, was often bypassed by physicians and parents not wanting to label an infant as retarded or not aware of the wider scope of eligibility.

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In short, the potential for a coordinated system existed, but as yet the pieces were still put together as a mosaic -- separate entities which might deal with the same clients. The only major gap in this picture was the lack of a center-based facility. Therapists traveled long distances in all kinds of weather to reach their small clients at home and dragged equipment from house to car to house. Those seeing the same child rarely had time to communicate with one another or to observe each other's work. Messages were often delivered through the parent: "When _____ comes, ask her about _____ " was not an uncommon request. Longingly, providers and parents looked to the two cities to the north and south of the region, each with its well-equipped and staffed center. According to regional catchment areas, these centers were to serve several counties, with their boundaries bisecting the Bath-Brunswick region. From a central planning perspective, it appeared that residents could easily reach one of these centers. Interstate 95 runs through the region from north to south with access points at regular intervals, seemingly making it possible to centralize highly technical professional expertise.

In reality, no children from the Bath-Brunswick region were attending programs at the centers. Not only was transportation a hardship, but also people were not oriented towards these cities. Usually, their shopping and medical needs could be satisfied in the commercial centers within the region. Many lacked reliable transportation, shunned the interstate highway, and felt alienated by the impersonality and psychological distance of urban professionals.

One mother made a valiant attempt to place her four year old severely handicapped son in the preschool at one of the centers before giving up in exhaustion and desperation. Her son needed an integrated program of physical, occupational, and speech therapy, plus a group educational experience to reinforce the therapy, to stimulate him to use his intellectual capabilities, and to allow him to be with a peer group. This mother rose early, prepared the handicapped child and his younger brother for the 25 mile trip to the city. Each morning she had three hours to wait and then the long trip home with hungry, overtired children. Perhaps it was the sheer energy required, or the expense, or the exasperation when her bored toddler threw his shoe into the fountain at the "Mall" during one of those interminable mornings. The experiment ended after two weeks. "We must have our own center," was her conclusion.

Part of the task for Project SEARCH was to identify ways to stimulate the development of needed resources for the Bath-Brunswick area. A center-based facility quickly emerged as a priority. What was needed was a place where professionals could come together and combine their respective expertise for the benefit of each child; a place where parents could meet other parents and where they could work as a team with the local professionals; a place with which all could identify. No preexisting model would be imposed. The program would have to emerge from an analysis of the population to be served, and the specific design would be developed through a collaborative effort between consumers and providers.

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The Planning and Preparation Process

Assessment

The timespan between identification of the need and actual opening of the new program was just fifteen months. During that time, the planning and preparation process proceeded in several directions. Initially, a small group of professionals from different agencies began meeting with the purpose of assessing the need. They compiled a list of children by age, type of handicap, services currently offered, and services needed. Project SEARCH assumed responsibility for coordinating the effort and for researching the feasiblity of mobilizing other community resources.

The child count indicated that there would probably be 12-15 children a year under age five who could benefit from a child development program combining therapies with preschool activities. Each professional discussed the idea with a number of parents, and soon all envisioned an early childhood center with age-appropriate learning and therapy activities for children with many different types of disabilities. At first the group considered applying for a federal grant but soon abandoned that prospect, since local funding would eventually have to be found. They decided to try to put together sufficient pieces from local sources, thus assuring continuation and local control.

Coordination of Existing Services

One additional factor soon became apparent. The mosaic-like service structure would function as a hindrance to collaboration around a new program which must fit into and complement existing services. Efforts to increase contacts and firmly establish linkages between providers should go on simultaneously with efforts to implement a center-based program. Hence, the spring and fall of 1981 saw a two-pronged attempt: to find the means to open a center and to change the mosaic into an interconnected unit.

With regard to the latter, Project SEARCH invited all direct service providers to attend a series of meetings held over a period of eight months. As individuals became personally and professionally better acquainted, barriers to effective collaboration were gradually broken down. The group began to deal with common problems and to devise ways of combining their expertise and limited time to better serve individual children even before a center could be opened. By early 1982, there was agreement to channel all new referrals through Project SEARCH and to establish weekly intake and review meetings attended by representatives from all key agencies. Physicians were contacted individually, and a meeting was held with them to explain the purpose and functioning of the team. Their cooperation has been very good.

Search for Location and Staff Funding

Parallel with the coordination meetings, a painstaking survey of the region for a center location and staff funding took place. Ideally, space donated at no cost was sought. Churches, schools, public and private agencies, and prominent individuals were contacted, but no concrete solution seemed to be forthcoming. However, by June 1981, several organizations

had offered help with pieces of a plan once the major framework was in place. Some would give volunteer time; others might donate supplies or equipment; preschool teachers would help with suggestions for activities or materials; and agency professionals would lend their expertise in programming for individual children. All were excited at the prospect of "our own community program," yet none could provide the framework.

Rural areas are places where people wear several hats and where informality rather than bureaucracy usually prevails. These factors directly led to the child development program's location at the hospital in Bath. The director of Physical and Occupational Therapy at the hospital was also one of the therapists chasing all over the region and one of the participants in the interagency coordination process. Her in-hospital role as a department head gave her knowledge about prospective changes in hospital services and the responsibility for improving the efficiency of her own department. The hospital was in the midst of renovating the patient wing and moving the pediatric ward from an area next to the emergency room to the second floor. The director knew of no plans for using the current pediatric space. She questioned whether that was the answer to their quest for a center location and a cost-effective way to reorganize part of the present out-patient therapy service for young children. Would the administrator respond positively?

Linkage with Hospital

In late summer 1981, the director teamed with the Project SEARCH coordinator and laid out a strategy for approaching the hospital administrator with documentation of need and a proposal not for a new program, but for an innovative approach to extending current services. In a meeting with the hospital administrator, the director stressed the number of children, the degree of agency coordination already achieved in the area, the readiness of the community to participate, and the futility of therapists continuing to spend half their work week in cars. Although counterarguments to possible objections were prepared, they were never voiced. The administrator immediately became excited by the idea, and, more importantly, no plans existed for the soon-to-be-vacated pediatric space. His only question was "What else do you need?" Before the close of the meeting, he had agreed that the hospital would hire a half-time teacher-therapy assistant and would cover the cost of start-up equipment and materials through available foundation or service organization funds. Some specialized therapy equipment would come from the existing department budget, and the Bureau of Mental Retardation adaptive equipment specialist would work on corner seats, prone boards, bolsters, and etc. as part of her regular consultant role. The hospital maintenance department would take care of renovations to the space according to specifications.

Suddenly two women, the P.T. and O.T. Department Head and the Project SEARCH coordinator, found themselves co-directors of a dream about to become a reality. Target date for opening the new program was originally set for early January 1982, later changed to mid-February. In the intervening months, the specifics of the program were planned. Sharing the task of director proved to be advantageous. Overseeing the space renovation and ordering materials were done from within the hospital, while preparations for intake, arranging transportation, and contacting parents were done from outside.

Parents, preschool teachers, therapists, and child development specialists joined together to decide on equipment and materials and on the layout of the room. With help from the Maine Children's Resource Center at the University of Southern Maine, Project SEARCH organized a regional workshop which culminated in a proposed floor plan, lists of all necessary equipment, and concrete suggestions for organizing each session. A local cabinet maker designed and built a special cut-out table to fit available space; another is making a special sand and water table for use with prone standers. Hospital personnel donated books and toys. The finished room and character of each day at the center directly and indirectly reflect the input of a great many people.

The Program Model and Daily Operation

The gap in services in the Bath-Brunswick Region was because of a need for a center-based early intervention program for mentally and physically handicapped children needing therapy on a regular basis. Parents and therapists wanted to be able to work together and to organize therapy time realistically. Home-based therapy required a block of time per child per week. There was no flexibility. If the child could concentrate for only 10 minutes at a time, the therapist was not able to work with another child and then come back. The child development program at the hospital was designed to allow for flexibility and individual levels of tolerance among children as well as for parent participation and for collaboration between therapists.

Presently, the program is held five mornings a week for 2½ hour sessions. Up to five children attend each session, and most are scheduled for two sessions per week. The children are grouped according to their developmental ages and therapy needs. Diagnoses of children currently attending include cerebral palsy, arthrogryposis, Down's Syndrome, sacra dysplasia, and mental retardation.

Referral Process

A child may be referred to the program by physicians, therapists, parents, or the preschool coordinator. The central intake team recently established for the region is responsible for intitial screening and further referral to the directors of the child development program who complete the actual intake.* This includes a home visit, the scheduling and completion of appropriate evaluations, and contact with the child's physician(s). After a staff meeting to discuss a preliminary program and appropriate grouping, the child begins to attend. A few weeks later, a formal meeting with parents is held to finalize an Individual Service Plan (I.S.P.) which is reviewed and updated quarterly.

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*The Project SEARCH Coordinator functions both as temporary co-director of the child development program and as intake team chairperson.

Schedule of Activities

Each session is divided into five major time blocks, circle time, gross motor, fine motor, sensory stimulation, and self-help activites. Snack time allows for group socialization as well as for emphasis on individual feeding programs. The specific activities within each time period are selected according to the objectives in a child's I.S.P. Children receive individual 30-minute sessions of physical and/or occupational therapy within the classroom, although the time may be broken into several short periods. The occupational therapist also works with the children at snack time and during other group activities as time permits. On Wednesdays, both therapists are in the classroom for the entire morning; on the other days they alternate. Parents are encouraged to ask questions and observe therapy. They are welcome to remain with their child, but are also free to choose to spend the time for themselves or to meet informally with other parents (i.e., in the hospital coffee shop). Approximately once a month, a parent meeting, seminar, or workshop is held on topics of their choice; they may also schedule individual conferences at any time.

Two or three times a month, a speech therapist from a cooperating agency visits the program to consult with both parents and staff. Children needing individual therapy are referred to this agency. Therapists from the Bureau of Mental Retardation are available for consultation and to assist with evaluations. Team conferences are held for each child at three-month intervals. A case management approach is utilized to assure that each child's program is appropriately carried out and monitored.

Educational and Medical Aspects of the Model

The framework for the child development program attempts to combine aspects of both a medical and educational model. All available medical data is reviewed prior to setting up an I.S.P. The child's physician(s) is notified of enrollment in the program and of team conferences. Progress notes are sent to physicans on a regular basis. Every six weeks an orthopedic clinic is held within the center to give therapists and parents an opportunity to confer with the specialist on further treatment plans. In accordance with the hospital's policies, medical referrals must be obtained before a child is scheduled for therapy.

The therapy program takes place within an education setting. The emphasis is on learning skills necessary for daily living, school readiness, and successful interaction with peers. Components of the educational model are widened by the use of multi-disciplinary team conferences and I.S.P.'s to parallel the school's Pupil Evaluation Team process. Goals and objectives are set up for each child in four categories: 1) gross motor; 2) fine motor; 3) cognitive; and 4) social-emotional. As the child approaches school age, the special service director for his or her school district participates in the team conference.

Community Participation

Interest in the program has generated volunteer help which supplements the regular staff and results in almost a one-to-one ratio of adults

to children on some days. Since several children lack all self-help skills, volunteers are playing a vital role. Those working directly in the program include an occupational therapist not presently employed, a woman interested in art therapy, and a student in the health professions curriculum at the regional vocational school. Other volunteers are assisting with transportation -- both individuals and organizations such as the Red Cross and Navy Wives Clubs. The two directors are also exploring ongoing arrangements for student placements with the vocational school and a local college. Several organizations have already donated or offered to donate funds for large equipment purchases or to cover the cost of ongoing expenses such as materials for adaptive equipment. Area preschools have lent equipment and are interested in cooperative arrangements whereby some children may begin to attend their programs in conjunction with the hospital program. The local newspaper has provided good coverage, and a TV station has already filmed one morning session. Community interest and support continue to grow, and the co-directors are often asked to speak to service and civic groups throughout the region.

Advantages of the Hospital Setting

From the beginning, the hospital setting has proved to be extremely advantageous. First of all, the child development program is part of a year-round, well-established, and important community institution. That association lends credibility and visibility. Many sources of funds are available through the hospital, including private foundations and service organizations which make contributions to be used at the discretion of the administrator and trustees. The occupational and physical therapists were already on the hospital staff and seeing many of the children at home. They were more than ready to reorganize their work week to schedule three mornings each in the program.

In the course of a week, many staff members stop by to observe this unique service which is now an integral part of their workplace. Through their social and family contacts, they act as important bearers of information to the community about young handicapped children. Without any direct effort, a network is emerging, through which offers of volunteer assistance as well as referrals are beginning to come.

The various departments of the hospital have played essential roles in assuring the success of the project. The maintenance department carried out all renovations superbly and continues to respond immediately to all requests ranging from putting up picture hooks to constructing a flannel board or frame for a bean bag throw. Each day the kitchen staff prepares the snack menu according to the teacher's instructions. Housekeeping, laundry, and clerical staff also are important. Diapers, tissues, towels and other small but essential items used in the daily routine are all available within the hospital.

Since the child development program is an out-patient service of the hospital, bookkeeping and billing are handled by the patients' accounts office. Parents are billed only for individual therapy time and can be referred to the Patient Accounts Manager to discuss financial problems

or insurance coverage. Most of the children are covered either by Medicaid or their family's major medical policy. In cases where there is no adequate insurance coverage, the hospital may reduce or waive fees as part of its obligation to provide free service to the community. No child is being denied individual therapy because of the parents' inability to pay full or partial cost.

Finally, the hospital is facilitating informal contact between the therapists and many area physicians. The latter are in the hospital regularly and without disrupting their schedule can take a minute to answer a question or quietly observe a particular child in play and therapy. The opportunity to hold clinics or consultations with physicians at the site of a child's program is greatly increased because the physician is so often there.

The hospital also is deriving benefits from the child development program. Recent press and TV coverage of the program have naturally meant a great deal of positive publicity for Bath Memorial, not just in the Bath-Brunswick region, but also statewide. The child development program has created a spirit of pride and excitement within the hospital. In the community there is a growing recognition of the special innovative role in the total health care delivery system that a small hospital can take as in-patient stays decline. There is only praise for the administrator and trustees who responded so quickly to the need.

Transferable Procedural Methods

The child development program at Bath Memorial Hospital answered a need in a region of central, coastal Maine. Although the particular program and the resources used to develop it may not be suitable for other communities, the basic principles and procedural methods are transferable. They were key factors in assuring the successful development and implementation of an appropriate plan.

Community Organization Approach

First of all, a community organization approach was utilized. A complete overview or profile of the region was carried out to determine not only how organizations and individuals already working with young handicapped children might contribute to the establishment of a center, but even more importantly, to pinpoint other sources of support and assistance. Besides factual data, the community study yielded valuable subjective impressions concerning the degree of community cohesion, the parents' relationships with and attitudes toward service providers, and on the general tenor of feeling in the region toward this particular client group. Two important conclusions were drawn.

1. Many residents strongly identified with the region and would support a totally local program to benefit their own population. They were less inclined to support either a satellite of an existing urban program or one administered by a state agency. Voluntary contributions would be especially difficult to mobilize for the latter.

2. Many parents of very young handicapped children have difficulty accepting a program located in an agency identified solely for the handicapped, and area physicians hesitate to refer, particularly if the child's diagnosis is uncertain. The search for an appropriate location and sponsor took into account the above information.

Utilization of Community Resources

Once the hospital setting was assured, a concerted effort was made to utilize the skills and expertise of parents, service providers and other members of the community to design and carry out the actual plan. As a result, there is a feeling of identification with the program and a commitment on the part of many to make it work.

Regional Coordination Project

One other factor appears to have played a significant role in determining the successful outcome -- the participation of the regional coordination project. All of the preliminary and procedural work was channeled through Project SEARCH. The coordinator is independent of all direct service agencies and has never been perceived as a threat to or in competition with them. This special position allowed the coordinator to initiate and serve as facilitator for the parallel process of improving collaboration between professionals and tackling interagency coordination problems.

Conclusion

Two final notes are worthy of mention. First, building a comprehensive continuum of interconnected services is a lengthy process and must be tackled in incremental steps. Each small step requires enormous amounts of energy and commitment -- people investing of themselves and believing that it can be done. Second, not everything happens by design; auspicious moments and fortuitous circumstances will occur which must immediately be used to the best advantage. Sometimes it is the one "lucky break" that provides the framework within which other pieces can come together. Both of these elements were important in building the child development program at Bath Memorial Hospital. The specifics may be different in other small communities, but the right combination of resources to solve service needs for young handicapped children and their families lies there waiting to be discovered and mobilized.

COORDINATION OF MEDICAL SERVICES FOR HANDICAPPED INFANTS THROUGH A COMMUNITY MENTAL HEALTH, MENTAL RETARDATION SERVICES BOARD PROGRAM: A MODEL

Stephanie Parks

Fulfilling medical needs as well as educational, psychological, and environmental needs is especially difficult in the first few years of the handicapped child's life. Not only are acute health care needs significant during this period, but also a variety of diagnostic exams are often required to determine the specific medical needs relating to the handicapping condition.

In rural communities it is especially difficult to coordinate, synthesize, and perhaps even recognize the many medical needs of the handicapped preschooler. Local pediatricians are often few and far between and are rarely trained in developmental disorders.

One Infant Intervention Program which is clinically coordinated with the Virginia Department of Health's Crater Child Development Clinic is attempting to solve some of these difficulties by acting as a locus of management for the medical needs of handicapped infants. Although the program is administered through the local Mental Health and Mental Retardation Services Board, it is the program staff's close relationship with the Child Development Clinic that has enabled them to recognize, integrate, and assure that the infant's medical needs will be met within the program's psychoeducational model.

This paper will attempt to explain how the program's relationship with the Health Department evolved, and then will describe the coordinated efforts which have facilitated, not only the medical care of infants in rural areas, but also the credibility of early intervention.

Evolution of the Infant Intervention Program

This evolution fits well within the perhaps worn, but often true, cliché "the right person being in the right place at the right time." In this case the right person was the Clinic Director of the Crater Child Development Clinic, a pediatrician who not only had a special interest in pediatric developmental and behavioral problems, but also in developing special projects. The right places were the Crater Child Development Clinic and the Developmental Disabilities Unit administered through the Department of Mental Health and Mental Retardation, both located in Southside Virginia, where there were no available programs to serve handicapped infants. The right time was the Spring of 1978, when demonstration projects were being encouraged for the handicapped when federal funding was available.

Organization and Functions of the Crater Child Development Clinic

The Crater Child Development Clinic is one of 14 diagnostically oriented multi-disciplinary clinics operated by the Department of Health in Virginia. This network of clinics is set up almost exclusively for diagnostic work for children with developmental problems and serves children from birth to 21 years of age who reside in a multi-county region. The region served by Crater is primarily rural. At the Crater Child Development Clinic there is a pediatrician, nurse, psychologist, social worker, and educational consultant. Diagnostic evaluations consist of a pediatric physical exam, nutritional assessment, psychological evaluation, and social work history. Following this one to two day workup, the child is then referred to community services, when indicated, for the recommended "treatment(s)."

Steps Taken to Provide Infant Intervention

However, when an infant had received this evaluation and was found to have a developmental disability, there were no available resources in the Crater region to provide comprehensive intervention in the community. The Clinic Director's frustration over this lack of resources prompted him to attempt to expand the traditional diagnostic role of the Child Development Clinic to include treatment services for the handicapped preschooler as well. After several calls within the (then) Department of Health, Education and Welfare, he was led to the Developmental Disabilities Unit administered within the State of Virginia. That program representative was very interested in his proposal, not only for the merit of serving this underserved population but also because Developmental Disabilities typically did not receive many proposals from Health Department programs.

After applying for and receiving the grant to start an Infant Intervention Program, subsequent problems arose within the bureaucratic maze of the Health Department's Personnel Department. Establishing new personnel positions for the new program was impossible because of the long time it typically takes to fill positions within the State system. In addition, there was a personnel freeze in effect within the Health Department. With grant award in hand, and no fiscal agent, it appeared that this project would end before it actually began.

Establishment of the Infant Intervention Program

Fortunately, the Clinic Director approached the local Mental Health and Mental Retardation Services Board with the problem and they agreed to act as the fiscal agent for the program. It was agreed that the Crater Child Development Clinic would provide the administrative and programmatic supervision, clinical management, and supportive services as initially proposed.

Over time, the program has fallen under the auspices of Mental Health and Mental Retardation by "default" because, although the State Health Department endorsed the program, they were not willing nor "set up" to administer the program via the Child Development Clinic. However, had Mental Health and Mental Retardation been the original grant applicant, the relationship and strong ties with the Crater Child Development Clinic would not have been as strong nor as viable. That association, with the Clinic, has fostered the credibility of Infant Intervention with the medical

community and has facilitated the integration of the infant's medical needs within the child's educational program.

Coordination of Infant Intervention Program with Medical Community

Having the Crater Child Development Clinic's director and pediatrician initiate this program may be seen as the major force in establishing a positive relationship with the medical community. The pediatrician sent out introductory letters and set up informal meetings with the local Health Departments, private pediatricians, and hospitals to inform them of the new program. During the first year the program received more referrals from the medical profession than from any other source!

Provision of Transition from Diagnostic to Treatment Services

The clinical coordination of the Infant Program with the Clinic lends itself well to a smooth transition from diagnostic to "treatment" services. Although the programs are not housed within the same office, they are located within the same building complex, which is very important for identity purposes and convenience. All infants enrolled in the program receive the diagnostic evaluation already described, through the Clinic. The Infant Program staff attend the Clinic's team staffings, thereby allowing them to be close at hand to ask questions about contraindications, implications of the medical aspects upon the child's program, etc. Frequently the Clinic pediatrician refers the infant for further specialized workups (neurology, genetics, orthopedics, etc.). The Infant Program is immediately aware of these recommendations and can act as a coordinator in helping to schedule, arrange transportation when necessary and, help insure that these recommendations are actually implemented. Follow-up calls to these "outside" referrals can be made by the Clinic pediatrician who, in turn, can easily interpret to the Infant Program's staff relevant findings. As the program has gained credibility with medical specialists, the Infant Program staff can frequently make these follow-up calls with success. Through this kind of coordination the handicapped infant residing in rural areas is able to have his medical needs integrated and assured within his psychoeducational plan.

In addition to the initial pediatric exam and medical specialty referrals, the Clinic pediatrician continues to be involved with the infants in the infant program via formal and informal consultations. Any changes in the infant's physical status can immediately be reported to the pediatrician for on-the-spot advice, consultation, support, or additional medical referrals.

Acquisition and Maintenance of Credibility

Because the Child Development Clinic already had an excellent relationship with the local Health Department the infant program gained, by association, an almost instant credibility with the public health nurse and nurse practitioners. Since the majority of infants served receive routine medical care through the Health Department, the program maintains close contact with the nurses through phone calls and personal visits. In addition, each group supports the other with the families to promote home follow-up of both medical and psychoeducational needs.

Continuance of Communication

Although the program has had its share of experiences with unanswered phone calls, skepticism and conflicts with the medical community, for the most part contacts have been positive and valuable. Communication has been facilitated through the Clinic pediatrician and by sending the Intervention Plan, assessment, and progress reports for each child to all medical professionals involved. Specific pertinent findings are sometimes highlighted with a marker to draw attention. It has been found that sending reports not only helps keep physicians aware of the Clinic staff's intimate involvement with the infant, but at times has been educational as physicians find that Infant Intervention is not simply play or "stimulation."

Another helpful venture which has facilitated integrating the medical needs of the infant into the Infant Intervention Program has been for the infant's "casemanager" to accompany the parent and the child to the specialized medical workups. This has eased parents' transportation difficulties and fear of being intimidated by medical terminology, and has met general support needs enormously. It has also given teachers and therapists the opportunity to meet the physician personally, and help carry out any further recommendations they may have for the infant. Physicians also realize how the Infant Program's involvement can be of help to them when trying to establish the child's history and current status. Many of the children served by the Program have illiterate and/or mentally retarded parents with whom the physicians have difficulty communicating. The medical personnel are most grateful when the Infant Program staff can help interpret medical information to parents, answer questions they may have, and obtain information needed by the physician.

Conclusion

For those who are trying to establish ties with the medical community in a sparsely populated location and who do not have the set of circumstances that this Infant Intervention Program was fortunate enough to have, there are avenues which facilitate the effort. For example, include medical personnel on advisory boards or committees. If there is a physician associated with the program ask him/her to help solicit these members. Work on disseminating awareness of the program, its benefits and its credibility to the medical community. Most of all, reinforce the physicians' efforts by letting them know how their input is valuable to the efforts of the program.

BUILDING A RELATIONSHIP BETWEEN AN EDUCATIONAL AGENCY AND THE HEALTH CARE SYSTEM IN A RURAL AREA

Sharon Kiefer

The compelling need for collaboration between the health care system and the educational system in the provision of comprehensive services to handicapped children and their families has been well documented (Jones and Brazelton, 1977). But how can community-based early intervention programs relate to the vast and established health care system? How can they involve primary care providers in planning and implementing comprehensive services for the handicapped child and his/her family? The literature provides few answers to these essential questions.

Having never received a single referral from physicians in their community, the staff of a small community-based program for young handicapped children in rural Virginia decided to seek ways to relate more effectively with the health care system. The program, Child Development Resources (CDR), developed a strategy for impacting physicians, nurses, public health agencies and other health care organizations. The problem was approached from both a short term and a long term perspective. The immediate, short term objective was to increase the number of children referred to the community-based program by physicians. The long term objective was to impact physicians at the training level so that those coming into the field were aware of both the effects of early intervention and the services provided by the educational program.

Results of the CDR effort were highly positive. Physician referrals were increased 100% while at the same time, the average age of referral was reduced from 18 months to less than six months of age. In addition, CDR eventually became a training site for primary care pediatric medical residents from a large urban university.

Child Development Resources is a small non-profit agency now serving handicapped and developmentally delayed infants, birth to two, and their families. Interdisciplinary assessment and staffing, as well as program planning are offered to each child every four months. Parents, who are members of the intervention team, are trained to be teachers and advocates for their own children.

However, in July of 1975, CDR was serving approximately 32 children, ages two to eight, and their families in a center-based, non-categorical classroom program and had been funded to begin services to 16 infants, birth to two, as of July 1, 1975 by the Bureau of Education's Handicapped Children's Early Education Program (HCEEP).

Increasing Referrals

The Problem

In spite of an operational Child Find program, financed by state Development Disabilities monies, which had been operating for 16 months, not one child in the CDR program had been referred by a private physician, clinic or hospital. Three had been referred by the health department. The average age of children referred was slightly higher than 17 months.

Child Find activities included a number of important and tested strategies. A massive community awareness public education campaign, using all available local media as well as a speakers bureau, was mounted. A comprehensive community survey included door-to-door canvassing. Inter-agency agreements to establish service and referral agencies were negotiated In addition, written and telephone contact was made with area physicians. A presentation about services was made to the medical society.

Obviously, if the strategies developed for the Child Find effort had been as effective as thought possible, referrals from health care organizations would have been forthcoming. Since they were not, new strategies had to be developed if CDR was to serve the very youngest handicapped children in the community.

Solution Strategies

The CDR staff determined that the most valid referrals might come from two major sources: 1) medical professionals and 2) the parents themselves. Referrals were regularly coming from parents, but not from the medical profession. It was decided that health professionals were needed on the CDR staff to develop and implement specific strategies for impacting the medical community. Two public health nurses were hired.

Public health nurses were selected because public health nursing education incorporates clinical knowledge and skill in working in a community-based setting, including coordination of services and home visiting skills. The public health nurses, one hired full-time and one hired half-time, were assigned responsibility for receiving and screening referrals to the program; continuing Child-Find; and acting as liaison between the educational agency (CDR) and the medical community.

Development of effective liaison included the following steps:

1. All health resources were catalogued, both public and private;
2. Those resources likely to be primary sources of medical care and referral sources of preschool handicapped children (birth to five) were identified;
3. Leaders or senior members of primary resources were identified; and
4. Individuals within each resource category were catalogued.

After the resources were identified, the list was analyzed in order to determine primary targets. Professionals most likely to see prospective

CDR clients were defined as primary targets. In rural areas, general practitioners, family practice physicians, and obstetricians were included in the primary target group. Primary targets selected were: 1) private physicians (particularly pediatricians), family practitioners, and obstetricians; 2) public health medical directors, pediatric clinic physicians, nurse practitioners and public health nurses; 3) neonatalogists and pediatrics specialists such as neurologists; and 4) hospital nursery and obstetrical nursing staff.

At the same time, specific materials for medical personnel were prepared. Materials included a short, factual brochure and program abstract outlining criteria for referral, program services, qualifications of program staff, referral forms, and materials which could be used in the waiting room.

The CDR staff approached both individual physicians and groups of physicians. All private physicians serving the catchment area who were primary targets received an office visit from CDR staff members. Appointments were made for the visit, and paid for by CDR when necessary. Presentations were made to groups of area physicians through continuing education programs at local and regional hospitals.

During one six month period, 40 local private physicians were contacted and visited. The director of newborn nurseries and the directors of neonatology at two university medical centers were also contacted and visited. In addition, presentations were made to the medical staff of the local community hospital and the regional hospital.

As new physicians have moved into the catchment area, CDR staff have visited their offices and invited them to visit the center. The three new pediatricians and four of five new family practitioners have accepted the invitation and visited.

The approach to the health department and nursing staff differed from the approach to physicians in that initial contacts with directors were made to obtain permission and support for meetings between staff. Support from supervising staff was critical to reaching direct service personnel. For example, contact with the Director of Nurses was essential before CDR staff talked to nurses. These meetings, titled "exchange of information" inservices, were informal, sometimes occurring over lunch or as part of a regularly scheduled staff development inservice. Information about referral procedures and services offered was provided by CDR staff. A dialogue was initiated regarding procedures that could be used so that agencies could work together to provide services to the very young handicapped child and his family.

Follow-up procedures were initiated to nurture the relationship between CDR and the health care system. Referrals received immediate acknowledgement. Copies of screening and assessment reports were forwarded to appropriate health care professionals as soon as possible. The referring physician or nurse was encouraged to participate in program planning for specific children attending the ongoing staffings. When, because of time constraints or other commitments, a physician was unable to attend

staffings, his/her input was sought by phone. Continuing consultation with the primary care providers was one strategy used for integration of professional input and cooperation.

Results

While in 1974-75 CDR had never received a single referral from health related professionals, as a result of the activities designed to increase physician referrals today 54% of CDR's referrals come from physicians. See Table 1. Furthermore, physicians are increasingly sensitive to both the needs for early intervention and the services offered by CDR. Referrals are being made at increasingly earlier ages. See Table 2.

Table 1
Percentage of Physician Referrals to CDR (1974-81)

1974-75	0%
1975-76	5%
1976-77	13%
1977-78	40%
1978-79	32%
1979-80	54%

Table 2
Average Age of Referrals at CDR (1975-80)

Year	Age in Months
1975-76	17.35
1976-77	11.79
1977-78	10.00
1978-79	6.30
1979-80	5.60
1980-81	5.70

Training Medical Students

The Problem

While the short term effort was focused on physicians already practicing, the long range goal was intended to influence the curriculum of medical students in training. The positive relationships established in the short term strategy strengthened other contacts. While visits to medical school deans did not lead directly to curriculum change, the contacts did lead to appointment of the CDR director to the State Genetics Advisory Board. A medical school faculty member with responsibility for supervising primary care medical residents was also on the advisory Board. Over a period of time he came to see the relevancy of a laboratory experience at CDR as a small part of a 30 day practicum experience in community pediatrics. Late in 1978, the first medical resident came to CDR for a laboratory experience.

The Solution

The practicum experience at CDR is one and one-half days in length. Two to four residents rotate through CDR during 10 months of each year. The goals of the experience are as follows:

1. Provide pediatric residents with information about the need for and benefits of intervention services to young handicapped children and their families.

2. Provide information regarding intervention services available at CDR and other community-based educational programs.

3. Provide activities and information related to the role of the physician as a member of the interdisciplinary team serving handicapped young children.

Scheduling the practicum is done by a CDR staff member, usually the public health nurse, who makes the arrangements and accompanies the residents during their visit. The nurse has the responsibility for emphasizing the ways the primary care pediatric role meshes with early intervention goals. A major part of the practicum experience is related to increasing medical participation and expanding the physician's role in early intervention strategies.

The one and one-half day practicum includes the following:

1. Observation of program components
   a. Introduction to developmental assessment
   b. Observation of assessment and staffing
   c. Observation of group activities with children
   d. Observation of a home visit

2. Discussions related to various aspects of early intervention, including the benefits
   a. Rationale for educational intervention with preschool handicapped children, ages birth to two
   b. Comprehensive services needed by preschool handicapped children and their families, and those services available in Virginia
   c. Interaction with parents and staff for purposes of clarifying the role of the interdisciplinary team
   d. Discussion of legal aspects related to early intervention, including P.L. 94-142

3. Discussion of the physician's role on the intervention team
   a. Parents' perspective as it relates to the medical system
   b. Ways to expand the physician's role in early intervention

Results

Both direct and indirect, results of the pediatric practicum experience at CDR are positive. The change in the medical school's community pediatrics curriculum has occurred. The physician who supervises the residents' practicum training also evaluates the impact of the experiences on his/her students. The fact that the program has continued is a demonstration of its relevancy. The impact of the experience on the residents is probably most significant in that they are most struck by the problems the parents have had. Seeing the problems and the growth that young handicapped children experience at CDR provides a different viewpoint, away from the medical facilities, that enable the residents to deal with the problems from a broader perspective.

Summary

In summary, community-based programs in rural areas need to reach out to the medical community if comprehensive interdisciplinary services are to be available to all preschool handicapped children and their families. Through careful planning, implementation and evaluation, a relationship with the medical community can be established and nurtured to the benefit of handicapped children and their families.

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MICE PROJECT: A NEW HAMPSHIRE MODEL OF A HEALTH-EDUCATION RELATIONSHIP

Mary Morse
Barbara Kruger

Over the past decade the New Hampshire Division of Public Health Services, Bureau of Maternal and Child Health/Handicapped Children, Handicapped Children Section, has worked dilegently at establishing a history of service delivery to young handicapped children. This Title V agency has accepted the legislative mandate calling for the demonstration of a leadership role in planning and delivering health and medical services to mothers and children in New Hampshire. With the philosophical orientation that health is not merely the absence of disease, but is also a state of well-being, the Bureau has been instrumental in effectively accessing and utilizing the resources of other departments in an ongoing and coordinated manner. Because of this attitude and approach, the blind and visually handicapped children under the age of three in New Hampshire receive quality services even with today's cut budgets and decreased services to populations with special needs.

Historical Background

Initial Recognition of Needs

In 1972, the New Hampshire Division of Public Health Services took a leadership role in re-evaluating the service delivery system for young handicapped children and in planning for efficient, cost effective methods of providing comprehensive and coordinated child and family services. Even in those "primitive" times, before the conception and passage of such broad legislation as P.L. 94-142 (Education for All Handicapped Children Act) and S.S.I. (Supplemental Security Income) legislation for disabled children, particularly significant issues and needs were delineated. They included the need for a multi-disciplinary team approach in obtaining and reviewing pertinent information in order to plan comprehensive services for young handicapped children and their families and the need for interagency cooperative efforts in planning and implementing comprehensive and coordinated services. This interagency concept was considered a critical component to be developed and was based on the premise that no single agency could, or should, provide full services to a high risk population (e.g., young handicapped children and their families). Also considered essential was the need to develop a service system that was not competitive with existing services, but rather was supportive and consultative to other service providers as the need determined.

Establishment of MICE

Consequently, in 1974 a review and advisory Multi-disciplinary/Interagency Core Evaluation (MICE) Team, representing a variety of statewide services, was established. The functions of the advisory team included:

1. Develop a procedure to identify and refer young handicapped children.

2. Develop a process to obtain and review health, medical and developmental records of clients and social-developmental histories of families in order to determine the risk characteristics and capabilities of each child referred for services and his/her family.

3. Develop a process to recommend and alert families to appropriate resources within their communities that could provide components of a comprehensive and coordinated care plan.

4. Develop a mechanism to insure the provision of information, technical assistance and educational services to both the families and the increasing number of professional personnel who would be requested to provide various service components to a population whose characteristics would very likely be unfamiliar to them -- very young handicapped children.

In order to develop the multi-disciplinary/interagency concept, visually handicapped and blind preschoolers, their families and involved community personnel were delineated as the test population. Members of the MICE Team were selected to represent varying social, medical, educational, and other rehabilitative agencies and would participate in Team activities as a component of their routine professional duties, with the consent and support of their respective departments.

State Department of Education Support

The MICE concept was implemented initially with administrative and fiscal support from the New Hampshire Department of Education. In June, 1979, the New Hampshire Attorney General ruled that public education monies expended for handicapped children less than three years of age was in violation of the New Hampshire statute. New Hampshire law mandated provision of educational services for handicapped children ages three to twenty-one, thereby restricting provision of any services to children ages birth to three.

Public Health Services Support

The Attorney General's decision had created a situation where young blind and visually handicapped children had no specialty service system available to them anywhere in the state. As a result, the New Hampshire Division of Public Health Services decided they must facilitate the provision of services to this population. Their rationale for this was based on several contributing factors.

Low incidence of sensory handicaps. Sensory handicaps are of such low incidence (as compared with many other handicapping conditions) and the demographic distribution is so widely spread, that it is not administratively or fiscally realistic to expect community resources to have personnel trained and experienced in managing this specialty need.

Lack of services for sensory handicapped. Nor is there, in New Hampshire, a designated agency soley responsible for providing services to all sensory handicapped persons (although under State and Federal law all handicapped children ages 3 to 21 are provided with a free and appropriate education.

Importance of early intervention. As indicated through research, the critical stage for the most normal development of all life skills (cognitive, physical, social, emotional) is the first few years postnatal. Sensory impaired children can have an increased chance of developing to their maximum potential and acquiring efficient usage of residual hearing/vision if identified early, if provided with a promotional health-oriented service, and if specialized training, remedial and compensatory techniques are introduced at the time of developmental readiness.

Critical needs of parents. Parents of infants identified as having an irreversible handicap experience a period of grief that has often been compared to the grief one experiences when a loved one dies. This period of grief and trauma occurs at a time when the family is least prepared to cope with the unexpected. Emotional and social support for parents must be provided to increase their sense of competency so that adequate bonding and nurturing may occur, parental capacities be maximized and realistic expectations and goals be developed.

MICE Project for Visually Handicapped and Blind Infants

Through yearly grants awarded from 1979 to the present by the New Hampshire Division of Public Health Services to provide statewide direct developmental services to visually handicapped and blind children, ages birth to three, the MICE Project was able to continue its activities. The grants, which are administered through a private agency contract, enable the MICE Project to serve as a model of service agencies pooling resources and energy to meet the health, medical, therapeutic, educational and social needs of young handicapped children.

Organizational Framework

The administrative and structural workings of the program were instrumental in establishing the coordination and cooperation necessary for a working relationship among health care professionals and educators. The service-in-kind contribution of office, office equipment and telephone for the project director (a special educator) and the administrative assistant are utilizedfor the purposes of linkages with the health care system, early identification, and comprehensive/coordinated services.

A reviewing physician from New Hampshire's primary diagnostic facility and social service consultants from the Bureau for Handicapped Children, New Hampshire Division of Welfare, and New Hampshire Division of Mental Health and Developmental Services contribute time to agency activities. Thirty-five percent of monies granted through the public health system are utilized to subcontract for professional time from certified and experienced educators of the blind and visually handicapped.

Intensive liaison activities are ongoing with the Instructional Materials Center of the New Hampshire Educational Services for the Visually Handicapped. The Center is funded with public education monies for visually handicapped and blind children, ages 3 to 21. The liaison enable the MiCE Project to purchase and use their equipment and materials.

Benefits to the Educational System

The benefits to the educational system of this health-education relationship, beyond the allowance of services to be continued to birth to three year old blind and visually impaired children, are numerous.

1. Early identification of blind and visually handicapped children to assist Local Educational Agencies in long range planning.

2. Consultation to New Hampshire Educational Services for the Visually Handicapped for continued utilization of the existing health care system in New Hampshire.

3. Continuity of services through educators trained and experienced to work with blind and visually handicapped persons.

4. Sharing of pertinent information such as intake, medical, health and developmental records.

Conclusion

The health-education relationship as outlined has resulted in a 260% increase in the last two years of visually handicapped and blind children, ages birth to three referred to the MICE Project. This dramatic increase in early identification cannot, and should not, be construed as an increase in the incidence of visual handicaps among this group of children. Rather, it is a testimony to the effectiveness of a new type of relationship: a collaborative/cooperative approach to meeting the needs of young handicapped children by the health and education service systems.

ADMINISTRATION AND ORGANIZATION OF COMMUNITY HOSPITALS AND MEDICAL CENTERS

Introduction

The final section provides an overview of the administration and organization of community hospitals and medical centers in order to enhance non-medical professionals' understanding of the system and their ability to work within that structure. Tesh and Strauss explain the various roles of medical professionals who work with children and their families at a medical center. They explain the different functions of a medical center (teaching, research and service) and the inherent confusion that results for those not familiar with the system. Tesh and Strauss, both instructors of nursing at a medical college, offer their insight and suggestions for making contacts within the medical center, sharing and obtaining information on particular children and maintaining open communication.

Axtell, the administrator of a community hospital, offers an examination of hospital organization to enhance non-medical personnel's ability to work with a medical institution. Using Williamsburg Community Hospital as an example, Axtell explains its organizational framework, primary and secondary missions, coordination with other community agencies and the incurred expenses of the hospital's operation. Axtell concludes by emphasizing that cooperation between community hospitals and other community agencies is feasible through direct discussion of needs and an understanding of the operation of the hospital and its necessary priorities.

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THE MEDICAL CENTER: INTERACTING WITH THE MULTIDISCIPLINARY TEAM

Esther M. Tesh
Sarah S. Strauss

Care of and service to handicapped children and their families require the involvement of many professionals in various settings. One of these settings is often the medical center. Transition for the child from a small individualized program in a community service agency to a large medical center for diagnostic evaluation and treatment can be overwhelming not only to the family, but also to those nonmedical professionals involved. An understanding of the system of the medical center, the roles of professionals who work with children in the medical center and how to reach them and share or obtain information facilitates coordination between the community agency and the medical center.

The System

Large medical centers have three important missions: 1) teaching, 2) research, and 3) service. Many medical centers are either integral parts of a university or are closely affiliated with one. Within the medical center are schools of nursing, medicine, dentistry, and allied health. Because of these missions, medical centers are referral centers to which individuals having a wide variety of complex health problems come when local community health agencies and professionals cannot meet their needs. Many handicapped infants/children and their families are part of this group. They are usually recipients of services delivered by specialists in the hospital or clinics, but are also impacted by the teaching and research missions of the university medical center. For example, handicapped infants may have students and their teachers from several disciplines (medicine, nursing, occupational therapy, nutrition, etc.) involved in their care, in addition to the regular staff. Or, the parent(s) may be approached by a researcher (graduate student, faculty member, or clinical staff) and be asked to participate in a research project. The research mission is accomplished in a variety of ways. Many faculty at medical centers conduct research ranging from biological and physiological research in laboratories to research with patients in a variety of settings. This research is directed toward ultimately improving people's care and well being.

For individuals who are not familiar with the setting of a medical center, its large size, required to implement the service, teaching, and research missions, can be formidable. In addition, the large numbers of students/faculty/personnel required to deliver care often create confusion (i.e., "the arm does not seem to know what the leg is doing."). Adding to the confusion of those served by medical centers and to the confusion of their advocates from the local community, many of the medical professionals speak a foreign language, "medical jargon." Abbreviations without

explanation and long, often unpronouncable words are bantered about (McCollum, 1975, p. 188). The goals of the next few sections of this paper are to provide community agency personnel who are not familiar with the inner workings of these referral centers with a map that they can use to navigate in this strange world.

The People in the System

Often the professionals within the medical center function as an interdisciplinary team. They may see the child individually, but then later meet together to share findings and arrive at a diagnosis and treatment plan for the child and family. Trying to keep each professional and his/her particular function straight can be a monumental task. A family is likely to see many of the following individuals who provide services such as those described in Table I.

Table I.

Nursing

Staff Nurse----a registered nurse who is responsible for nursing care of the child and for supervising others who provide care, e.g., licensed practical nurses (LPN's) and nursing assistants or aides.

Charge Nurse---a registered nurse who has overall responsibility for patient care during the particular shift that she is on duty. During the day shift this person may be the Head nurse.

Clinical Nurse Specialist--a registered nurse with a Master's degree in Nursing who is often involved in coordination of nursing care and care provided by other disciplines for children who present many types of health problems.

Community Health Liason Nurse--a registered nurse who works with both hospital and public health departments and has responsibility for arranging home care, follow-up after discharge, and referral to appropriate agencies.

Medicine

Pediatric House Officer (HO)--a physician who may be either an intern or resident who is completing a period of study and patient care after medical school before going into private practice.

Attending Physician--a medical doctor who has completed several years of study and practice and is a member of the medical school faculty.

Specialist House Officers & Attending Physicians--medical doctors who serve in the same capacity as the physicians described above, except they are in other specialty areas e.g., orthopedic surgery, child neurology, neonatology, pediatric surgery, etc.

Therapies

Occupational Therapist--facilitates the development of fine motor movements, e.g., reach, grasp, manipulation, hand/eye coordination.

Physical Therapist--facilitates the development of gross or large muscle movement e.g., getting in and out of chair, sitting, moving on hands and knees, balance, negotiating stairs, etc.

Speech Therapist--evaluates child's ability to produce speech and acquisition of prelanguage concepts, e.g., object permanence, and language abilities. Provides therapy to improve speech production and facilitate acquisition of cognitive or thinking skills underlying language acquisition and ultimately, speech production.

Audiologist----Tests hearing and recommends measures for correction of hearing deficits.

Respiratory Therapist--administers inhalation and chest physiotherapy for children who have problems with lung infections or difficulty handling mucus.

Dietician------Helps plan foods to meet special dietary needs and ways to prepare and serve foods to enhance likelihood of child eating the food.

Child Life Worker or Play Therapist--provides a program of play and activities to meet developmental needs of children and to assist them in coping with hospitalization and/or illness. May be in charge of play room.

Pediatric Pharmacist--an expert in the medications children are likely to receive. This individual is likely to be involved in teaching about drugs, especially seizure medications.

Dentist-- Provides dental care and teaching for the child. Some dentists specialize in working with children with developmental problems. Monitors effects of drugs on teeth and gums, especially the seizure medications.

Teachers-- Evaluate abilities of child to perform developmental tasks, especially those related to cognitive function; determine types of stimulation along with other team members needed to promote development and learning.

Social Worker-- Serves as a resource when family difficulties exist and assists in referral to family service agencies and financial resources and assistance; promotes family functioning and in some instances is involved in coordinating services with outside agencies.

Chaplain-- Available to child and parent(s) to assist in coping with child's diagnosis, plans for treatment, etc.

Navigating the System

There are many mechanisms for entering the system. Certainly, anyone from an outside agency can contact a professional within the medical center concerning a particular child, family or problem. If there is uncertainty about whom to contact first, the nurse on the hospital unit or in the clinic is an excellent resource person. Charge or head nurses, nurse clinicians, and clinical nurse specialists can often provide information about the current status of the infant/child and family as well as providing information about and access to other disciplines, e.g., medicine.

Ideally, information about the unit to which a child is admitted (e.g., phone number, name of health professionals caring for the child, etc.) can be obtained directly and immediately. Occasionally, the child's teacher or service provider may have accompanied a child and the parent(s) to the hospital/clinic, or may be in touch with the parent(s) or health professional shortly after admission. Often, however, information is not obtained during the crisis of admission; therefore the teacher/service provider is faced with initiating the contact after the child has been admitted. The following strategy can be employed in the first communication with the nurse (or other professional).

1. Obtain the phone number of the unit/clinic from hospital information--then ask to be connected if possible.

2. When the phone is answered, introduce yourself and ask to speak to the nurse who is caring for Susie Jones today. Specify that you wish to talk to the R.N. in charge of the baby's/child's care. The nurse will usually not answer the phone. If the call is made to a clinic, ask to speak to the nurse in charge of the "neurology" (or other specialty) clinic. Another strategy that may be employed is to send a note with the parent asking the physician to call after seeing the child/family, but before the family leaves the clinic. Often information needs to be shared that will influence decisions made by the physician and/or other health team members regarding the child/family's plan of care. If this strategy is employed, be sure to remain near the phone to receive the call.

3. Once the R.N. comes to the phone, reexplain your interest in Susie Jones and ask how Susie is doing.

4. After obtaining information about Susie's condition, ask if this nurse frequently cares for Susie: If not, who does?

5. If the nurse is not Susie's regular nurse, and if she does not know who Susie's regular nurse is (she may be a float nurse from another unit), ask her if the charge nurse would know. Then ask her to get the charge nurse on the phone. Find out from the charge nurse who Susie's regular nurse is. Also find out a good time to call this nurse to get reports and to provide information that may assist in caring for Susie.

6. Ask if the nurse clinician or the clinical nurse specialist is involved in Susie's care. If Susie has been in the hospital for a while or is a frequent visitor to clinics, she is probably known by these individuals. Find out the names of these nurses and leave a message and/or a number for them to call. Often nurses (and other professionals) can and are willing to call you on the WATTS (or SCATS) line to communicate. This is helpful if you are not on a WATTS line and suffering from budget problems.

7. Nurses are good information sources about the current resident or intern who is caring for Susie and who the support service people are. The resident house officer is responsible for Susie's day-to-day medical care. He/she can also return your calls. Find out a number at which this individual can be reached. Remember residents rotate every few weeks, so be prepared to talk to a different person from time to time if Susie's hospital stay is prolonged.

8. Be prepared to share programming needs and routines and special appliances/equipment, e.g., positioning the spastic infant, with nursing (and medical) personnel. Each infant/child has a nursing care plan. Shared information can be recorded on the care plan and used by the team.

9. Also remember that if information is shared only with the attending physician and/or residents, the information may or may not be communicated to the nurse who manages the day-to-day nursing care of the child/infant, e.g., bathing, feeding, positioning, stimulation, and play (along with therapies).

10. Last, if anyone uses any words/terms that you do not understand, ask them to explain in "plain English." As you share your information, be sure not to use your own discipline's jargon.

Conclusion

The medical center is a resource that community service providers rely on heavily to provide the best treatment and care for the children and families they serve. Once the barrier of communication difficulties is overcome, the community agency personnel can remain an integral part of the child's care and the interchange of information can be quite beneficial to all involved.

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THE LOCAL COMMUNITY HOSPITAL: ITS ROLE AND FUNCTION AS A HEALTH CARE RESOURCE IN RURAL COMMUNITIES

Kenneth H. Axtell

Hospitals in America generally were established by community leaders who determined a need existed in their area for a health care facility. Typically, community hospitals offer medical, surgical, obstetrical and pediatric services to patients. The patients' conditions are short-term or acute; thus their lengths of stay in the hospital are relatively short. In addition to acute in-patient care, most hospitals provide emergency and out-patient care facilities.

Hospital Organization

Hospitals in our nation are typically organized as non-stock, non-profit corporations. These corporations are governed by a Board of Directors or similarly titled groups of citizens broadly representative of the geographic area served. The assets of the hospital are held in trust for use by citizens and visitors in the area. Hospitals are managed by chief executive officers who are employees of their governing boards, answerable directly to the Board, and who serve at the pleasure of the governing board.

Governing boards delegate to their chief executive officers the responsibility for organizing the various disciplines in the hospital into a cohesive productive body. Governing boards delegate responsibility for medical staff organization to physicians.

Hospital medical staffs function through comprehensive by-laws, rules, and regulations. Critical to an effective and competent medical staff is a credentialling process through which all members of the medical staff must pass for membership and privilege delineation. This process verifies that the applicant is "who he says he is" and has progressed satisfactorily through the educational programs which he claims.

Membership on the medical staff of most hospitals is available to licensed physicians and dentists, and other licensed health care professionals as associate members by application on prescribed forms. Privileges to admit, treat and discharge certain types of patients is the second part of active medical staff participation in the hospital. Privileges are delineated to an individual physician based on his specialty education and specific procedures for which he has particular expertise gained through training and experience.

The ultimate authority and responsibility for all activities by the medical and hospital staff rests with the governing body. The governing body approves all policy and procedural guidelines for their institutions, and the by-laws, rules and regulations of the medical staff. The governing body approves all individual recommendations for medical staff membership

and delineated privileges. The governing body is responsible for assuring quality care is provided and that all applicable laws relating to health care facilities are being met.

Williamsburg Community Hospital: An Example

Leaders of Williamsburg Community Hospital believe that the foundation of local health care is the community hospital. They believe that the governing body, the medical staff and management have joint responsibilities to ensure that patients are receiving high quality care consistent with accepted standards of care and that the hospital is fiscally sound and efficiently operated.

Health care services are offered to all patients seeking care without regard to race, color, sex, religion, age, national origin or handicap. Services are offered on a personalized basis to enhance the dignity and worth of every individual.

To assist in offering personalized care to patients, the hospital management team maintains a pro-employee stance and attitude. Out of this has developed high performance and a genuine attitude of caring through provision of satisfying, competent, timely and professional services to all.

Organization

Williamsburg Community Hospital may be classified as a "typical" local community hospital in many ways. The hospital as a medical care institution is owned and operated by a non-stock, non-profit corporation organized under the laws of the Commonwealth of Virginia. Final responsibility and authority are vested in the Board of Directors whose duties include review and evaluation of:

1) Management,
2) Medical care,
3) Finance,
4) Educational programs, and
5) Community services.

Medical care programs, services and quality assurance review are provided and supervised by a duly qualified and organized staff of physicians, dentists and associated health care practitioners. All memberships and delineations of privileges are approved by the Board of Directors upon recommendation of the entire medical staff following the credentialling process.

Hospital employees are assigned to appropriate departments. Hospitals are highly departmentalized in order to provide specific services as ordered by the admitting physician. For example, the largest department in most hospitals is the nursing service. Professional registered nurses and licensed practical nurses along with supporting staff provide their special care to patients. Augmenting that care are employees in such departments as food service, cardio-pulmonary, physical therapy, pharmacy, radiology, pathology, building maintenance, financial services and medical records. While each department is a relatively autonomous professional employee group, each is interdependent on others. All services are coordinated through the senior management team.

Volunteer services are provided by the Hospital's Auxiliary. These services augment and enhance those provided by paid staff. The organization of the Auxiliary is approved by the governing board as are its by-laws, rules and regulations.

Primary Mission: Provision of Hospital Services

The mission statement of Williamsburg Community Hospital emphasizes the primary role of operating a general, acute care hospital. Specific services offered are justified by demand and are supported by sufficient resources to permit high quality, cost-effective delivery. Educational activities are designed to improve knowledge and skills of health care professionals, to improve health awareness and knowledge of the citizenry, and to augment patient treatment.

Secondary Mission: Meeting of Community Health Care Needs

The secondary mission of the hospital is to be a leader in meeting the total health care needs of all in the hospital service area. At the present time, this secondary mission is less developed than the primary. With care and concern, this mission can be enhanced and further developed, and thus become a viable force.

Williamsburg Community Hospital is an integral part of the health care system. The hospital staff responds to needs of the community as presented by the medical staff when they experience these needs in their practices. The staff responds to requests for services rather than creating the need or promoting the needs for acute services.

For many citizens and visitors, Williamsburg Community Hospital serves as the entry point into the health care delivery system through the Emergency Department. This department is always open and staffed by an emergency medicine physician and appropriately selected and educated nursing personnel.

The majority of patients enter the health care delivery system via their private physicians. It is upon the physicians' recommendation for hospital services that the staff responds by providing the care and the facilities.

Coordination with Other Community Agencies

Available to the residents are the facilities of the Public Health Department and numerous agencies offering assistance and expertise in specialized areas. It is to these agencies that special attention is focused to extend hospital-based services and to enhance those agencies.

In the Williamsburg area, specific services of the hospital and a listing of available facilities can be obtained through the Hampton Roads Health Information listing by either contacting that agency or Williamsburg Community Hospital. Any benefits which community-based agencies or program leaders believe could be expanded or enhanced via the hospital are discussed with hospital management. It is probably most advantageous for agency representatives to discuss areas of mutual concern on a regular basis.

Management personnel are interested in expanding their services beyond the four walls of the hospital. Mid-managers are interested in providing their professional services to agencies and thus expanding their departments. A secondary route of obtaining hospital services and cooperation lies in discussing needs with professionals in the hospital and later with senior management. The most effective means to reaching a goal of cooperation is the direct approach to either management group.

Hospital Expenses

Hospitals offer many services around the clock. Inherent in offering services at all times are high overhead costs because there are times when staff are less productive than at others. Since it is impossible to accurately determine demand, staffing may be heavier or lighter depending on many factors. The bottom line is an expensive, but available service in time of need.

Billing for services provided is the source of hospital revenue. Any assistance agencies can provide for their clients in interpreting charges and arranging for payment is greatly appreciated and in the best interest of all parties involved. Hospital bills are not considered confidential as are medical records. Most patients will gladly share information in order to secure financial assistance.

Williamsburg Community Hospital assigns in-patients to Patient Account Representatives (PAR) at the time of admission. A PAR business card is given to each patient listing the name and telephone number of his PAR. Any agency wishing to assist its client should contact the PAR. Such assistance is welcome. Interpretations of bills can be made and assistance in tapping payment sources can be provided. If sources outside the client or his family are unavailable, payment plans can be tailored to reasonable requests.

Williamsburg Community Hospital first offers its services to patients in need. Arrangements to pay for these services are made concurrent with treatment via members of the family or upon discharge from the hospital. Discounts are offered for cash payments at time of service. Cash payments include those payments made by a valid credit card. Discounts are offered for pre-payment. Pre-payment amounts and discounts are developed with Patient Account Representatives and the patient or his respresentative.

Conclusion

The example used here, Williamsburg Community Hospital, is a valuable community asset and an integral part of the health care delivery system. The hospital staff are anxious to be of service to those who need help. They, like other community hospitals, are anxious to expand their services to agencies whose management believes there are possible areas of cooperation. Direct discussion of needs most usually dictates how they work together. Direct discussion is often initiated through professional department managers or with senior management staff. By understanding how a local community hospital is structured and the priorities and functions of the governing board and the staff, other community health and education oriented agencies can strive to obtain the optimal cooperation and coordination of services to the community.

About the Handicapped Children's Early Education Rural Network

The Handicapped Children's Early Education Rural Network is an association of professionals representing education programs for young handicapped children in rural communities. Members are drawn primarily from projects supported by the NCEEP, Office of Special Education, Department of Education. Formed in 1978, the Rural Network undertook to provide a voice for rural America's young children and their families. The Network aimed to increase educational opportunities for this population through the accomplishment of a variety of activities. Participating projects also intended to enhance their own effectiveness in providing education and supportive services in rural areas. For further information, contact:

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